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NEWS Release

For Immediate Release

Topic: Birth Defects Registry

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Date: December 1, 1999

Mississippians can now begin to get an idea about what kind of and how many birth defects affect babies born here, thanks to a new law that empowers The Health Department to establish a birth defects registry.

While the state has made progress through the decades in reducing infant mortality due to birth defects, complex challenges remain in understanding and preventing the large number of defects that are today the leading cause of infant mortality.

Understanding the problem comes through documenting and analyzing the frequency and distribution of birth defects. Such a compilation of information, a Birth Defects Registry, helps families of babies with birth defects immediately become linked by public health workers to primary care physicians, specialists, and other appropriate resources for their infants.

For the past three years, the agency's program has worked with the University of Mississippi Medical Center and the Centers for Disease Control and Prevention to plan a surveillance program of infants with congenital malformations and certain genetic diseases.

The Birth Defects Registry Law, Section 41-21-205 of the Mississippi Code, became effective July 1997. The legislation established a Birth Defects Registry in the Mississippi State Department of Health, authorized the State Board of Health to adopt rules to govern the operation of the program, and authorized The Health Department to conduct certain investigations and related activities such as targeted intervention, education programming, and resource

allocations.

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Birth Defects Registry – Add 1

The law mandates the State Board of Health to specify the types of information to be provided to the Registry and the persons and entities that are required to provide such information to the Registry.

According to the law, the State Health Officer could appoint an advisory committee to assist in formulating the Registry. The committee has representation of parents of babies with birth defects, a medical geneticist, nurses and physicians who take care of mothers and babies in the private sector, the University of Mississippi Medical Center, and the Mississippi State Department of Health county health departments.

Registry goals are to monitor, regularly and systematically, the births of children with defects for changes in incidence or other unusual patterns that could suggest preventable causes; to help prevent secondary disabilities by linking families of children with birth defects to appropriate providers; to inform physicians about available resources for affected children and families; and to develop a case Registry for use in epidemiologic and genetic studies.

Among Mississippi's 42, 917 live births in 1998, 658 were reported on their birth certificates to have congenital anomalies. This number constitutes a rate of 1.5 percent in the birth population, well below the national average of 4 percent; this does not account for birth defects unrecognized or not recorded at the time of delivery or those that become apparent well after hospital discharge.

The Mississippi Birth Defects Registry will collect reports on certain principal birth defects from birth to one year of age and other defects found later in life. Birth defects may be present at birth or may take months or years to be recognizable and may be diagnosed singly or in a cluster in an individual.

By definition, a birth defect is an abnormality of structure, function, or metabolism whether genetically determined or a result of environmental influences during embryonic or fetal life. A birth defect might be present from the time of conception through the first year after birth, or later in life.

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Birth Defects Registry – Add 2

Many children are born with preventable birth defects. Neural tube defects, for example, are 80 percent preventable by folic acid supplementation before and early in pregnancy. In fact, an estimated 50 percent of birth defects are preventable with current knowledge.

All confirmed birth defects cases falling under the purview of the agency's Early Intervention First Steps Program will be reported to that Program for notification of patient's primary care physician within the prescribed time period. The notification will be entered into the Registry database for quality assurance purposes.

Anyone can submit a report of a birth defect at any time during an affected person's life. The Health Department prefers to have the child's physician submit the birth defect report within the first year of life by sending a mandated Birth Defects Reporting Card to the Registry. The cards are available to all hospitals and physicians that deliver babies on a regular basis or provide health services to children.

Because birth defects might not be apparent or be diagnosed at birth, providers who serve children are also required to report birth defects when first suspected or observed. Birth Defects Reporting Cards will be made available to these providers. Individuals can contact the Mississippi Birth Defects Registry to obtain cards.

Mississippi residents may contact the Registry for assistance at Mississippi State Department of Health, Genetic Services, Birth Defects Registry, 2423 North State Street, Jackson, Mississippi 39215-1700 or by phone at 601/576-7619.